

A Framework for Categorizing Social Interactions Related to End-of-Life Care in Nursing Homes

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Purpose: Almost half of people age 85 and older who die annually in the United States die as nursing home residents, yet because it is not always clear who is close to death, not all residents who might benefit from end-of-life care receive it. The purpose of this study is to develop a framework for organizing social interactions related to end-of-life care and to characterize the social construction of dying in two nursing homes. **Design:** Secondary analysis of qualitative ethnographic data collected before the death of 45 residents who were selected for the study on account of their “declining” health status. **Methods:** Field notes, medical chart data, and transcribed interviews corresponding to 45 residents in two nursing homes in a large Midwestern city were analyzed using qualitative descriptive methods guided by symbolic interaction and role theory. The data were also grouped by resident to facilitate the development of cases that illustrate the categories of social interactions. A second reader also categorized all the resident cases into one of five categories as a means of verifying the model. **Results:** A new framework of five categories to name the stance toward the possibility of dying is presented and illustrated with cases. The categories include: *dying allowed*, *dying contested*, *mixed message dying*, *not dying*, and *not enough information*. Cases are provided to illustrate the importance of recognizing the impact that social interactions can have on care. Over half the resident cases were classified as mixed message dying or not enough information, which speaks to the ambiguity regarding care plan goals

found in the two nursing homes in the study. **Implications:** Social interactions related to the health care and dying status of a nursing home resident help to construct a social reality, and that social reality can affect the care the nursing home resident receives. Conversations about goals of care, and how these goals will be operationalized are important issues for discussion among residents (to the extent able), family, staff, and physicians. Social interactions, or the lack thereof, matter.

Key Words: *Palliative care, Social constructionism, Symbolic interaction, Role theory, Qualitative, Goals of care*

There is confusion about the type of medical care that is in the best interest of people in advanced old age, many of whom are affected with advanced chronic illnesses. Over the past half century, medical and pharmaceutical interventions have been developed to postpone death (Fried, 2000). But postponing death is not avoiding death. With more people experiencing death in the context of advanced old age and with advanced chronic illness, it can be difficult to develop consensus about when palliative concerns should dominate care plan goals. Nowhere is this confusion more apparent than in nursing homes.

It is not always clear which nursing home residents are close to death. Residents who appear to be at death's door may get a second wind, and residents whose health appears to be stable may die suddenly in their sleep. Chronic illnesses can endure for years. Thus, even informed people can disagree on when dying begins. The focus of this paper is not the *physical* reality of dying, but rather the *social* reality that is constructed or created by the main people involved, that is, the nursing home

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resident (to the extent cognitively able), family members, staff members, and physicians. Considering whether a resident may be dying is important because it can affect the type of care a nursing home resident receives. A focus on palliative care goals is considered best practice care for people approaching death; palliative care is interdisciplinary care focused on the relief of suffering and support for the best quality of care for people facing life-threatening illness, and for their family members, regardless of the stage of the disease (National Consensus Project for Quality Palliative Care, 2004).

This article is a secondary analysis of qualitative data collected over 16 months in two nursing homes during a study that focused on end-of-life issues. The purpose of this article was to propose a framework for categorizing social interactions related to end-of-life care for nursing home residents.

Background

The nation's 16,000 nursing homes provide care to 1.5 million residents on any given day and close to 3 million people over the course of a year (CDC/NCHS, National Nursing Home Survey, 2008). Half of nursing home residents were aged 85 years (National Center for Health Statistics, 2007, table 104). Nursing homes provide care to a broad range of residents, including people in need of postacute rehabilitation care who are expected to return to their home and people in the advanced stages of chronic illness who will likely remain in the nursing home until death (Kane, 1996).

Twenty-two percent of the 2.4 million people who die in the United States every year die in nursing homes. Not surprisingly, the percentage increases with age. One third of deaths among persons aged 75 years or older and 42% of deaths among persons aged 85 years or older occur in nursing homes. In fact, among Americans aged 85 years and older, the nursing home is the most common setting of death (CDC/NCHS, Mortality Statistics, 2004).

The nursing home is a place where dying occurs frequently but not a setting known for excellent end-of-life care. A study of family member satisfaction with end-of-life care in different settings revealed that the nursing home has the most room for improvement (Hanson, Danis, & Garrett, 1997). Forbes (2001) reported a high degree of nursing home staff conflict regarding communications at the end of life. Kayser-Jones (2002) docu-

mented the lack of attention to comfort care needs in nursing homes. Wetle, Shield, Teno, Miller, and Welch (2005) reported that family members consider nursing home physicians "missing in action" at the end of life and that hospice enrollment occurs late in the dying process. Kaufman (1998) included the experiences of nursing home residents transferred to hospital intensive care units in her description of the "problem of death in America." Her ethnographic work vividly illustrated the ambivalence that can accompany determining goals of care when old age and advanced chronic illness intersect. Summarizing a review of the literature on end-of-life care in nursing homes, Oliver, Porock, and Zweig (2004) conclude with, "we know that at the end of life, there is commonly poor control of pain, low utilization of hospice, frequent hospitalizations, inadequate advanced care planning and communication, and family dissatisfaction with long-term care facilities" (p. 154).

Trajectories of Dying

The executive summary of the Institute of Medicine's document, "Describing Death in America: What We Need to Know," reported that designating a period of time as "the end of life" is a necessary first step to improving care for people approaching the end of life (Lunney, Foley, Smith, & Gelband, 2003). Yet, defining the onset of dying remains a persistent challenge. Four decades ago, Sudnow (1967) documented that the determination of dying is not always straightforward. George (2002) identified the failure to define dying as a fundamental problem in end-of-life research. Glaser and Strauss (1968) stated that dying must be defined as such in order to be reacted to as dying. Although there have been great strides in terms of research and clinical care for people who are recognized as dying, as a society, we continue to grapple with determining who is dying because, in part, of the growing ambiguity associated with contemporary dying (Bern-Klug, 2004; Hanson et al., 1997; Lynn, 2005).

In their book based on research on dying in the hospital setting, "Time for Dying," Glaser and Strauss (1968) emphasized dying as a temporal event. They discussed the notion of "trajectories of dying," which they also referred to as "perceived courses of dying" (p. 6). They reported that each hospital patient's dying trajectory can be graphed; it has duration (takes place over time) and shape (slope of approaching death). Glaser and Strauss

pointed out that a person's conceptualization of dying influences behavior: "How a patient, a doctor, a nurse, or a family member defines a dying trajectory becomes the basis for his or her behavior in connection with treating and handling the patient" (p. 55).

Dying trajectories have been used to operationalize the timing of dying. Pattison (1977) proposed that with the "crisis knowledge of death," one's mortal status is no longer theoretical. The crisis knowledge of death occurs upon the receipt of a serious diagnosis or following a serious accident. Pattison labeled the interval of time between the crisis knowledge of death and the time of the actual death as the "living-dying interval" of the death trajectory. He theorized that the living-dying interval had three phases: (a) the acute crisis phase, (b) the chronic living-dying phase, and (c) the terminal phase. Engle (1998) draws on Pattison's theory to recommend that all permanently placed nursing home residents receive palliative care.

The Medicare hospice benefit operationalizes dying as the 6 months prior to death. In order to invoke hospice benefits, Medicare beneficiaries must secure a physician who will document that if the condition runs its normal course, the patient is likely to die within the 6 months (Centers for Medicare and Medicaid Services [CMS], 2008).

Lunney, Lynn, and Hogan (2002) proposed four dying trajectories based on their analysis of Medicare claims data: sudden death, terminal illness, organ failure, and frailty. The latter three dying trajectories are common in nursing homes. They observed that older adults dying in the context of organ failure or frailty will have end-of-life needs that differ from those of people dying with a terminal diagnosis.

Theoretical Framework

The theoretical underpinnings of this study are symbolic interaction and role theory. Symbolic interaction emphasizes the importance that social interactions carry for the process of meaning making (Robbins, Chatterjee, & Canda, 1998). Blumer (1969), building on Meads' work, wrote, "symbolic interactionism sees meanings as social products We construct a reality, rather than encounter a fixed reality" (p. 5). Among symbolic interactionists, the "mind" is accepted as an independent reality (Stryker, 1972). People perceive

symbols—including language—interpret them and then react to them. How people define situations in their mind is important. As W. I. Thomas said, "When people define situations as real, they become real in their consequences" (Plummer, 1996, p. 228). Stryker explains, "the human being is actor as well as reactor, and he does not respond to the environment as a physical given but rather to that environment as it is symbolically mediated" (p. 20). When people enter a situation they must define and interpret the situation, which then leads them to ideas about appropriate behavior on their part, as well as on the part of others. If the people involved define the situation similarly and share similar expectations of behavior, the result is likely to be efficient organized behavior (Stryker).

As applied to this study, rather than encountering a set social reality about whether the resident is dying or what type of medical care the resident should receive, residents, family and staff members develop an interpretation of what type of care is in the resident's best interest based, in part, on their understanding of the resident's health situation and dying status. This interpretation of the resident's care needs can affect what type of medical care is pursued or avoided. Social interpretations of needs affect care.

This study also draws on an important idea from role theory. Social roles consist of rights, duties, and expected behavior (Turner, 1990). Applied to this study, social roles affect how nursing home residents behave and how residents are treated by family and staff members. The three primary types of social roles (related to health status) applied to nursing home residents are: the sick role (Parsons, 1951), in which the "patient" is expected to want to get well and to devote effort to following physician orders in order to regain health or recover from an acute exacerbation of a chronic illness; the chronic illness role (Estroff, 1993; Gordon, 1966; Hart, 1986; Mechanic, 1959), in which the nursing home resident is not expected to fully regain health but is expected to assume responsibility for complying with physician directives in order to maintain current health status; and the dying role. Unlike people in the sick role or chronic illness role, people considered to be dying have the option to forgo further medical interventions geared toward recovery without violating social expectations (Lamont, 2005). Indeed, in order to access the Medicare hospice benefit, the person *must* forego curative interventions related to the cause of dying (CMS,

2008). When a person, including a nursing home resident, is recognized as dying, it is socially acceptable to allocate remaining time and effort exclusively toward achieving physical, emotional, and spiritual comfort rather than continuing to pursue medical interventions aimed at recovery. Therein lies the importance of recognizing dying among nursing home residents; recognizing dying is a way to open the possibility for the residents' goals of care to focus on comfort.

Methods

The framework for organizing social interactions related to end-of-life care was developed as part of a secondary analysis of data collected during a study of quality of end-of-life care in two nursing homes. The original data were an excellent match for the secondary analysis because of the overlap in areas of interest, the overlap of research team members, the timing of data collection, the fit in terms of sample selection, and the consistency of data across sources, which are all criteria established by Stewart (1993) to assess the worthiness of using data for secondary analysis. The original study ("End of life in nursing homes: Process and outcomes of care," P. I. Sarah Forbes, 1999–2001: National Institutes of Health, National Institute of Nursing Research grant number R15NR04974) used an ethnographic approach to explore factors that influence end-of-life care mainly from the residents' and their family members' perspectives. In the original study, both quantitative and qualitative data were collected. In the secondary analysis, only qualitative data are analyzed.

Sample Selection

In the original study, a sample of "declining" residents was selected from two nursing homes in a large Midwestern city. "Declining" was defined using the National Hospice and Palliative Care Organization's 1996 *Medical Guidelines for Determining Prognosis in Selected Non-Cancer Disease* (see www.nhcpo.org) or postadmission changes such as functional decline; weight loss; personality change; social disengagement; an increase in infections, falls, or hospitalizations; and/or a decrease in cognition (Forbes, 2001). Family members of enrolled residents were invited to participate in the study. Residents were followed for up to 6 months. Some residents were in the study for days (they died or left the nursing home) and

others for months. The research team (including the author) spent approximately 8 months in each nursing facility for a total of 16 months in the field. Additional details about the data collection efforts have been published elsewhere (Bern-Klug, 2003; Forbes-Thompson & Gessert, 2005).

This analysis is based on the qualitative data associated with 45 (80%) of the 56 residents. The 12 residents who were excluded from the secondary analysis were removed because of the lack of qualitative data. In other words, there were no qualitative interviews with the resident or their family member due to the resident dying soon after enrollment, the lack of success in scheduling an interview with the family, or both. The original data were collected in 2000 and 2001.

Sample Characteristics

Residents ranged from 37 to 101 years; the mean age was 81 (*SD* 11.9) years. Five residents were younger than 70 years and five were aged 95 years or older. Two thirds were women; one third was African American. Most (91%) of the 45 residents required staff supervision or assistance to move from a bed or chair. Over half (53%) had decision-making skills that were moderately or severely impaired according to their most recent Minimum Data Set assessment. Nineteen (42%) of the 45 residents died during the study. Ten were alive more than 2 years after enrolling in the study.

Two thirds of the 44 family members of residents in the study were women (one resident had no family). Sixty percent of the family members were younger than 65 years, and 16% were older than 75 years. Nearly three fourths (73%) of the family members visited the nursing home at least twice per week.

Data Collection

The University of Kansas Medical Center's Institutional Review Board approved the original study and the secondary analysis. The interdisciplinary research team used the following strategies to collect three types of qualitative data: (a) observation data from observing the provision of care, such as dispensing medications, dressing wounds, transferring, and feeding, as well as observing nursing home routines such as resident council meetings, care plan meetings, activities, meal time, and so on; (b) interview data from formal and

informal interviews with residents (when cognitively able), family (in-person and by phone), and staff members; and (c) medical chart review. Observation occurred multiple times throughout the weekdays. Limited data were collected during the evening, at night, and on weekends.

Data Analysis

For the secondary analysis, all data referring to anything about each resident were marked and grouped by resident using QSR International's NUD*IST software program, version 5. The resident cases were then read to develop an overall sense of how the resident's health status vis-à-vis dying was perceived and any information about care plan goals. The data were analyzed through the lens of symbolic interaction and role theory in that clues to understanding how different people interpret the residents' dying status and ideas about appropriate care plan goals were identified by studying social interactions. Social interactions mean any oral, written (in particular medical chart material), or behavioral communication between at least two people. A list was made of all data that illustrate the resident, family or staff members' interpretation of the residents' health status or care plan goals. Once all the resident cases were read, and the list was completed, the items on the list were phrased as questions. All cases were re-read, and the questions were "asked" of the qualitative data (chart notes, interviews with the resident, family or staff member, and observations) in each resident's case. Examples of the questions include: Was this resident ever enrolled in hospice or on "comfort care?" How was comfort care operationalized in this resident's case? Did social interactions mention a do not resuscitate (DNR), durable power of attorney for health care, living will, or health care directive, or any other information related to advance directives? What was mentioned regarding goals of care? Were there any triggers in the case notes that prompted someone (the resident, family, or staff) to question whether the resident was possibly dying or whether goals of care should be changed to emphasize palliative care? For a full discussion of triggers identified in this study, please refer to Bern-Klug (2006).

Based on the responses to the questions, four categories of social interactions related to dying status and care plan goals were identified in the cases. The author assigned each resident's case to one of the four categories, at which time it became

clear that a number of the 45 resident cases in the secondary analysis lacked data related to dying status and care plan goals, and therefore, the case could not be categorized. A fifth category was then created, called, "Not enough information."

To test the categorization system, a research assistant (Peggy Sharr) read the definitions of the five categories and then read all 27 resident cases associated with the first nursing home and a random sample of 4 of the 18 cases from the second nursing home. The research assistant independently categorized each resident's case based on the established categories. Of the 31 cases reviewed by the second reader, all but five were classified in agreement with the author (84% agreement). When discussing the cases and categories, it became clear that the cases not similarly classified were situations in which different categories applied during the nursing home stay, with none dominating the case. To increase agreement between readers, it would be important to categorize the case at the same point in time.

Results

Analyses of the 45 resident cases were used to develop a framework to classify the social interactions related to dying status and care plan goals for each resident. The five resulting categories are: *dying allowed* (13 residents), *dying contested* (3 residents), *mixed message dying* (10 residents), *not dying* (4 residents), and *not enough information* (15 residents).

The social interactions related to dying and care plan goals in each resident's case fit into only one category at a time. However, the resident's case can switch categories over the course of the nursing home stay. The categories are briefly explained below and illustrated by a case study using fictitious names.

Dying Allowed

In *dying allowed*, there is consensus for a care plan dominated by the goal of comfort. (The term "palliative care" was not typically used by respondents.) Residents' health status is expected to continue to decline. Quality-of-life issues become more important than attempting to stay alive as long as possible. Social interactions related to *dying allowed* include situations in which the possibility of dying is openly accepted and the main people involved (including the resident to the extent able,

the family, and staff members) take the position that dying is not the worst possible outcome. In *dying allowed*, the decision makers deliberately forego medical interventions whose benefits in terms of comfort are questionable. In general, nursing home residents who were enrolled in hospice or who were charted as “comfort care” were classified as *dying allowed*.

A review of field notes revealed that not all residents who were on comfort care or who were enrolled in hospice were labeled as “dying” per se. In some cases, the justification for a transition to comfort care goals was based on consensus that there were no medical interventions available to reverse further decline and that the resident’s quality of life was already quite compromised. In some cases, the advanced old age of the resident and the advanced disease state were used to justify comfort care goals.

Case Example of Dying Allowed.—Mr. Davis, a former construction worker and widower in his late 80s, was diagnosed with peripheral vascular disease, congestive heart failure, hypertension, and diabetes. Both legs had been amputated. He had cognitive impairment that left him disoriented to time and place, yet he was capable of expressing opinions about pain, eating, and day-to-day needs. He answered mostly with a one-word response or a short phrase. During one visit, I mentioned to Mr. Davis that it looked as though he had gotten a haircut. He surprised me by saying, “No, not unless they knocked me out and did it.” His cognitive status fluctuated. Sometimes he hallucinated. Some days he yelled “Help me” for hours.

A completed durable power of attorney for health care (DPOA-HC) was found in his medical chart. His wife, who had been dead for years, was listed as the first DPOA-HC. His son, who lived three states away, was listed as a substitute. His DPOA-HC clearly stated that his agents had the power to discontinue treatment. There was a do not resuscitate (DNR) order in the chart signed by the physician. The DNR was completed around the time that Mr. Davis was admitted to this nursing home, 4 months before he enrolled in this study.

About a month before Mr. Davis was enrolled in the study, his medical chart documented that a feeding tube was being considered, but the son had decided against it. The physician’s section of the medical chart read, “Pts and son doesn’t think peg tube is a good option—thinks prolonging suffering. Keep him comfortable.” The nursing entry

read, “Physician’s phone order specifying comfort care only.” During a telephone interview with me, the son confirmed the chart notes by stating:

I asked them not to put the tube in. I don’t really know who was suggesting that we put it in, but I said that I didn’t want it in. Then there was no pressure whatsoever. The doctor talked with me about the benefits and the cons, and then let me decide. I knew he (father) would be opposed to it.

Mr. Davis lived 3.5 years after enrolling in the study. A review of his medical records revealed no instructions on how comfort care would be operationalized, despite the fact that comfort care was written in his chart. No examples of comfort care were observed by the research team during the 6 months the resident was enrolled in the study. Staff members did not articulate any changes to Mr. Davis’s care that were considered comfort care other than the decision to not insert a feeding tube. Despite the lack of comfort care operationalization, this case is categorized as *dying allowed* because there was consensus that comfort care—which in this case included no feeding tube—was agreed upon orally by the family and staff and documented in writing in the chart notes. This case illustrates social interactions resulting in consensus about wanting comfort care for the resident, even though the parameters of comfort care were not articulated. Aside from cases involving hospice, examples of residents on comfort care where comfort care was operationalized were rare. Therefore, although this case does not illustrate what full comfort care might look like, it is typical of nonhospice comfort care cases in the study.

Dying Contested

In *dying contested*, social interactions captured in the field notes demonstrate open disagreement about goals of care, the resident’s medical status, or the appropriateness of a medical intervention being considered. In *dying contested*, at least one of the main people involved in the resident’s care feels strongly that care should be comfort care dominated (allowing dying and death) and at least one other person feels strongly that care should be directed toward survival.

Case Example of Dying Contested.—Mrs. North was a 93-year-old widow diagnosed with advanced dementia “of the Alzheimer type,” glaucoma, depression, hypothyroidism, and constipation. She

spent each day in bed, generally on her side facing the wall. Staff transferred her to a wheelchair three times a day to take her to the dining room, where she fed herself with cueing from the staff. After eating, she returned to bed. Mrs. North said only a few words, only a few times a year. She generally showed little interest in anything other than eating. She had been living in the nursing home 5 years prior to enrollment in the study. Ten years ago, Mrs. North had been enrolled in hospice for a few months because of colon cancer.

Palliative care was important to the family. Before Mrs. North was admitted to this nursing home, her son and daughter-in-law secured assurances from the administrator that when the end of her life came, Mrs. North would be allowed to remain in the nursing home to die and not sent to a hospital. Because of previous negative experiences with different family members in other nursing homes, the daughter-in-law reported, "Before we put anyone in a nursing home now, we tell the administrator we are not coming in unless you promise that you won't ship them out if they are dying. This administrator promised to keep her here." Mrs. North's medical chart indicated that she had a living will, a health care directive, and a DPOA-HC, although a copy of the DPOA-HC was not found in the chart. The directive clearly indicated that she did not want surgery, cardiopulmonary resuscitation, dialysis, respirator, or tube feedings.

The daughter-in-law mentioned to me during the study, "At one point about a year or so ago, she stopped eating . . . just lost all interest in food. We told them, 'no feeding tube; check her directive, it says no tube.'" The daughter-in-law reported that the nursing home accepted the decision to forgo a feeding tube: "They accepted it. It wasn't our decision; it was hers." "We tell them, keep her comfortable. She is at the end." Later on during the same conversation, the daughter-in-law said, "We tell them (nursing home staff) no operations. Look at her. Look at her age. She has outlived all her brothers and sisters. Just let her be."

Two months before she died, there was an entry in the nurses' notes section of the resident's medical chart stating, "Called daughter-in-law to review discussion of care plan meeting. Discussed family wishes for hospice for Mrs. North when the time is right for this to be considered." The daughter-in-law said this about the meeting, "I asked them, 'At what point will you, as a nursing home, suggest hospice?'" The staff responded that hospice would

be brought in when Mrs. North was no longer eating or drinking.

About a month after that care plan meeting, Mrs. North was sent to the hospital because her eye condition worsened. The staff in the emergency room (ER) determined that her blood pressure was quite elevated. They could not determine why. A urine test was taken. The results were not available before Mrs. North was discharged back to the nursing home. The ER staff explained that there was nothing they could do for her.

The next day in the nursing section of the chart was a sentence indicating that the family did not want Mrs. North sent to the hospital. The following day, the urinalysis results returned indicating an infection. According to the nursing notes, the family was notified that Mrs. North was not eating or drinking and the family agreed that she should be sent to the hospital. My interview with the daughter-in-law revealed a different perspective.

When the family received the call from the nursing home saying that Mrs. North's blood pressure was still elevated and she had an infection, the family was in a car loaded with children leaving for vacation. The daughter-in-law was irate that the resident had been sent back to the ER. She told me, "What's the point of sending her back to the ER? The ER told us there was nothing they could do . . . I reminded her (the nurse) that the DPOA says she does not want to be prolonged if there is no solution." The nurse told the daughter-in-law that this was a "gray matter" and "now that she has an infection and she should go to the hospital." The daughter-in-law told me, "We didn't think it was a gray matter at all." She went on to say:

Maybe this is her body's way of shutting down. But no one wants to let her go, and that puts extra stress on us. The IV's, the ERs, the medications . . . just let her stay in bed and be peaceful. Nobody but hospice really deals with dying. Not the nursing home, not the hospital . . . My husband says, "This is so sad. She is in the hospital getting the bladder infection dealt with, getting her blood pressure controlled, but she is probably not going to get better anyway—she is probably dying—so they cure her blood pressure—so what! Let the lady die." We are prepared emotionally and spiritually. *It is so stressful to keep dealing with these health professionals who don't see the dying.*

The family enrolled Mrs. North in hospice when she returned to the nursing home. The daughter-in-law said, "Now the nursing home can't send her back to the hospital unless they check with hospice

first. That takes the heat off the family.” Mrs. North died in her nursing home bed 1 week after hospice started.

This case is classified as *dying contested* because the family repeatedly communicated that they wanted Mrs. North to receive comfort care at the end of life. During the study, the family considered Mrs. North to be at the end of life, although there was no indication that the nursing home staff did. Comfort care to the family meant hospice enrollment and no hospitalizations. The family and the nursing home disagreed about the appropriateness of hospitalizations until the last week of life when hospice became involved and supported the family in keeping the resident in the nursing home to die.

Mixed Message Dying

A lack of consensus about care plan goals can lead to *mixed message dying*. This category is different from *dying contested* because the main people involved in the resident’s care do not openly disagree; in fact, they may not realize that their opinions about the resident’s status and needs are not shared by others. The result can be contradictory messages about the resident’s status, confused goals of care, and inconsistent care.

Case Example of Mixed Message Dying.—Mrs. Anders was an 88-year-old widow who loved ice cream. Her closest relative (both in terms of proximity and affection) was her 79-year-old brother, who admitted her to the nursing home 10 years before she enrolled in the study. Among her medications, Mrs. Anders received medication for depression and insulin for diabetes. Sometimes she refused to take the medications. Both hips had been broken during the nursing home stay, and she was confined to a wheelchair. With some difficulty, Mrs. Anders was able to roll her wheelchair, but she preferred to be pushed. Her room was located at the end of the hallway, far from the nurses’ station, and farther still from the dining and activity rooms. Her chart documented that over the past year, she had been losing weight. When she enrolled in the study, Mrs. Anders weighed less than 90 pounds.

Mrs. Anders had no teeth or dentures. She had little jaw control. It was difficult to understand her speech, although she could articulate key words well. She spent most of her day in her room, either lying in bed looking out the window or sitting in her wheelchair with the lights off. Sometimes staff would wheel her to activities where she especially

enjoyed listening to music. She requested almond cookies and vanilla ice cream throughout the day.

Many times during the study, Mrs. Anders told me she was hungry. On occasion, I ate supper in the nursing home dining room with Mrs. Anders. By doing so, I observed that Mrs. Anders had difficulty swallowing. About half of what she put in her mouth she discretely regurgitated into her bib, unable to swallow. It was unclear whether the nursing staff assumed that the food missing from her plate was swallowed.

A review of Mrs. Anders’s medical record revealed that her code status was DNR. When asked about dying, she told me, “I am ready to die, but I like it here.” The social interactions related to Mrs. Anders were categorized as *mixed message dying* because of the lack of consistency in the understanding and interpretations of goals of care. Her brother relied on staff members to interpret her health status for him and to help him make decisions. Her brother stated that a few years earlier, the physician instructed staff and family to give Mrs. Anders anything she wanted to eat, with the hopes of stabilizing her serious weight loss. The brother began bringing her chocolate bars during his weekly visits despite knowing she struggled with diabetes. After a few months, she began to regain her appetite and her weight. The brother told me, “I (still) bring her two candy bars every time I come. They haven’t told me not to.”

Unbeknownst to them, the nursing staff was divided about “giving in” to Mrs. Anders’s food requests. Some did, others did not. They all acted out of their sense of her best interest. One afternoon, her brother and I were visiting with Mrs. Anders. A certified nurse assistant (CNA) was helping the roommate a few feet away. The CNA overheard Mrs. Anders ask her brother for ice cream. The CNA said, “She is eating too much sweets.” The brother replied that he thought that she could eat whatever she wanted, and the staff member said, “No. She won’t eat her supper.”

Later that day, I talked with the consulting dietitian about Mrs. Anders’s frequent comments about being hungry. The dietitian responded, “Well, she is dying.” I mentioned that she often requested ice cream and cookies and that some staff honored that request and others did not. The dietitian replied, “Well, she can have whatever she wants.” I mentioned that the week before, the staff refused to give her ice cream until she first drank a cup of water. The dietitian replied, “That isn’t right and that doesn’t make sense. She can have

whatever she wants.” The dietitian walked into the kitchen and returned shortly, stating, “I left a message that Mrs. Anders is to have ice cream with every dinner.”

After a few days, the medical director added a note in Mrs. Anders’s chart: “Resident may have food and fluids of choice at resident’s discretion.” The nurses’ notes for the same day indicated, “Resident wants ice cream and coffee throughout the day. Sometimes eats only ice cream. Order received for resident discretion in choice of foods and fluids secondary to comfort care.”

However, off and on for the remaining 2 months of the study, Mrs. Anders would tell me she was hungry and that she was not receiving ice cream. Some staff were denying ice cream on account of her diabetes. Others were giving her ice cream because she was dying. At the end of the study, the kitchen staff reported they did not know that Mrs. Anders was on comfort care nor did they know that she was to receive vanilla ice cream.

Not Dying

Social interactions related to *not dying* reveal that at least one of the main people involved with the resident’s care strongly believes that the overarching goal of care is survival. The resident may be considered to be “sick” or “chronically ill” but is not treated as though “dying.” The resident, family or staff member believes it is his or her responsibility to secure any medical care that may help to keep the resident alive. The intention is to fully pursue medical interventions aimed at survival. In *not dying*, other people may point out that the resident may be dying or suggest the resident might be better served by an emphasis on comfort care, but no one openly challenges the main decision makers.

Case Example of Not Dying.—Mrs. Grill was a widow in her late 70s. She was bed-bound, although the staff would help her into a wheelchair and take her to the dining room for meals. She could not form clear words. Occasionally, she would look at me intensely and say three or four sentences of words that I simply could not understand. Out of 50 words, I would be able to decipher one. The one word she could say clearly (besides “yes” and “no”) was “pain.”

As a resident in the current nursing home, Mrs. Grill developed a bedsore. At the time she was enrolled in the study, she had had the bedsore for over a year. It was a serious bedsore that caused

pain and severely limited both her mobility and the amount of time she could be in a chair. She was confined to bed most of the time.

Her medical chart listed the following diagnoses: irrational fears, multiple somatic c/o crying spells, anxiety, DMSI/cardiac arrhythmias, depressions, drug-induced hyperk, muscle spasms, D/T contractures, cataracts, acute shakes (aphasia), CVD, neurogenic bladder aspects, malnutrition, decub ulcer stage 4, chronic muscle pain, anemia, pancreatic, urinary retention, as well as six more conditions not documented in the study notes. Mrs. Grill was receiving 17 routine medications and 2 “as needed” medications. In her chart were a DNR form and a living will. Her daughter was listed as the DPOA-HC.

Three months before she was enrolled in the study, Mrs. Grill’s doctor (who was not the nursing home’s medical director) phoned the daughter to report that Mrs. Grill’s pacemaker battery was wearing out. The doctor asked the daughter if she wanted her mother’s pacemaker replaced, “on account of her age and her overall condition.”

The daughter remembered the phone call with the physician, and said to me, “I told that doctor, ‘You fix it. You give her a chance. If you fix it and we lose her—well then she didn’t have a chance . . . but we don’t know that now. You go on and fix it . . . Don’t just sit there and sign her death warrant, give her a chance.’”

Four months after the pacemaker was replaced, Mrs. Grill was rushed to the hospital to repair a hip that had broken when she was being rolled over in bed. After the surgery, the doctor told the daughter that Mrs. Grill might survive 6 months and that her bones were thin and fragile. After 5 days in the hospital, Mrs. Grill returned to the nursing home. In her medical chart 2 days after she returned were these notes: “When resident resumes going to dining room, she will be at restorative table . . . note new orders for codeine.” There were no indications in the chart that staff had talked with the resident or the family about goals of care or the possibility that Mrs. Grill was dying and might benefit from aggressive palliative care or hospice care.

Ten days later, Mrs. Grill was re-admitted to the hospital with a spiked fever. The nursing home called the hospital and reminded them to remove the staples from the previous surgery. The next day, the hospital called the nursing home to report that Mrs. Grill had “expired.” This case is classified as *not dying* because the family pursued

survival-oriented care despite clues from the physician that Mrs. Grill's overall health status and prognosis were poor. According to the daughter, the nursing home staff did not discuss Mrs. Grill's prognosis with her.

Discussion

Data from 45 residents were used to develop five categories of social interactions related to nursing home residents' dying status and care plan goals: *dying allowed*, *dying contested*, *mixed message dying*, *not dying*, and *not enough information*. No other framework for organizing social interactions related to dying status among nursing home residents was identified in the literature. The fact that the data on which these findings are based were collected prior to the death of the resident distinguishes the study from many other nursing home end-of-life studies. Indeed, during the study about half of the residents died, while about one fourth were still alive 2 years after enrolling in the study, thus underscoring the difficulty in identifying residents considered to be close to death.

The social interaction categories presented here are not static. A category change may be prompted by a change in health status, or a different *interpretation* of the resident's health status, which may result from people with different views socially interacting. The social interaction categories in this framework reflect a combination of (a) assumptions toward dying status vis-à-vis the nursing home resident, (b) opinions about the appropriate goals of care, and (c) assumptions about how the current or upcoming medical decisions fit into overall goals of care. Nursing home nurses and social workers should address these three issues with residents and family members at federally required quarterly care plan meetings, and more often as necessary. Physicians should discuss these issues with residents and family members upon diagnosis of a serious illness, when the health condition changes, and as care options change. The cases illustrate the importance of building and maintaining consensus about care goals, and operationalizing care plan goals in terms of consequences for care.

The study has limitations including that the findings are based on two nursing homes in the Midwest. Resident and especially family member's perspectives were emphasized in the study. A study limitation is the lack of commensurate data representing the physicians' and staff members' perspec-

tives. This study included medical chart data which can be misleading in that all care provided to residents is not recorded in the chart, and some of the care that is mentioned in the chart may not be provided. Also, although the number of cases per category is reported, the number should be interpreted with caution. One category was selected to represent each resident's case, although evidence of different categories was often present at different times during the nursing home stay. Numbers in each category would be more meaningful if the respondents had been randomly selected to be included in the study and if more residents had been included. Study strengths include 16 months of prospective data collection of multiple types of data by an interdisciplinary research team.

Case studies illustrate how social interactions create a social reality regarding resident needs and demonstrate that ideas about this social reality can have consequences for the care that nursing home residents receive. Two of the categories, *dying allowed* and *not dying*, occur when the social interactions signal agreement about the goals of care, although each category has a different goal. In *dying allowed*, there is agreement about comfort care, and in *not dying*, there is agreement about survival care.

One of the main ideas related to symbolic interaction is that a person's definition of a situation will influence behavior. Role theory tells us that social roles are accompanied by expectations about behavior. The current study looks at the social interactions related to building understanding about a nursing home resident's status vis-à-vis dying. Because of advanced old age and advancing progressing chronic conditions common among nursing home residents, residents' health status is often ambiguous (Bern-Klug, 2004). This ambiguity, especially if not recognized, can contribute to the difficulty in building consensus about appropriate care plan goals. According to symbolic interaction theory, if there is incongruence in how the situation is interpreted, then social interactions can become inefficient, disorganized, and stressful. These findings are consistent with that understanding.

Two social interaction categories, *dying contested* and *mixed message dying*, give a name to the confusion encountered in nursing homes related to care provided to some residents. The confusion is overt in *dying contested* and covert in *mixed message dying*. At least in situations categorized as *dying contested*, the main people involved recognize that there is a disagreement, which is a first step

toward resolution. The confusion about care plan goals in *mixed message dying* can endure until it is recognized. The consequence of this confusion was dramatic in the case of Mrs. Anders. Staff who considered her to be dying facilitated her eating what she wanted. Staff who considered her to be diabetic denied her requests for ice cream and cookies.

It is noteworthy that 15 residents (34%) lacked social interaction information (including goals of care documented in the chart) sufficient to categorize their situation other than *not enough information*. The lack of social interactions related to health status and care plan goals suggests a degree of obliviousness to the possibility of dying. The situation facing these residents will remain in this ambiguous state until a decision about a medical intervention is needed, someone asks for clarification about overall care plan goals or the resident dies. In the meantime, residents, family, and staff will make daily decisions about the care these residents receive, including what they eat and whether they should be sent to the hospital. In all, 25 of the 45 residents (56%) were represented by either *not enough information* or *mixed message dying*. It is difficult to understand how excellent care can be provided to residents when the overall goals of care are not clearly understood and agreed to by the main people involved.

These case studies illustrate the importance of recognizing the impact that social interactions can have on the delivery of care. The type of care residents received was related to what people considered to be the reality of the residents' situation; this is entirely consistent with role theory and symbolic interaction. The decision to forgo a feeding tube for Mr. Davis, the food available to Mrs. Anders, and the confusion over the appropriateness of repeated hospitalizations for both Mrs. Grill and Mrs. North were related to ideas about what care was in the resident's best interest.

The observation by Glaser and Strauss (1968) that people must be defined as dying to be reacted to as dying may explain why more residents in the study were not enrolled in hospice or receiving comfort care; they were not considered to be dying (despite the fact that they were enrolled in the study because of declining health). Reviewing the 13 resident cases coded as *dying allowed* revealed that the term "dying" was not always used in the recorded social interactions, perhaps because of the uncertainty about the timing of death or perhaps because of the stigma associated with dying or both. Instead, some of the residents in both

nursing homes were considered appropriate for comfort care or hospice care because of the recognition that medical interventions would not be helpful in addressing further expected decline. In *dying allowed*, the social interactions related to the residents' status reflect a consensus that the person's health is compromised to the extent that he or she is vulnerable to death. In other words, the risk of death was elevated, yet the timing of death may be uncertain. Social interactions reveal an open acceptance of the possibility of dying and death, and the importance of handling the situation in a way that does not impose additional suffering on the resident. These residents may not have been considered "dying" per se, but they could be considered to be at the end of life, on account of expectations of further unavoidable health declines and advanced old age.

Lamont (2005) defined the end of life as: "the period preceding an individual's natural death from a process that is unlikely to be arrested by medical care" (p. S13). Being recognized as "dying" is one passage to comfort care goals, but as documented in this study, it need not be the only way. If the broader notion of "end of life," rather than a narrow definition of "dying," prevailed in nursing homes, perhaps more residents would be considered appropriate for care plans that focused on palliation and comfort care.

Three insights related to hospice and comfort care were inspired by the findings. First, unlike the other categories, admitting a resident to hospice or comfort care (*dying allowed*) requires social interactions that result in overt consensus about the goals of care. This is not the case when survival care is pursued, as our health care system is geared toward survival care as the default, and little discussion is therefore required. Lynn (2005) suggested that this should be reversed and that the system should be designed so that rather than having to advocate to refuse medical treatment geared toward cure, patients and nursing home residents approaching the end of life would get palliative care that would serve them well, "without having to advocate . . ." (p. S17).

Second, enrolling a resident in hospice serves as a clear marker that this person's overall care goal is comfort. For example, it was not until hospice became involved that Mrs. North's palliative care status was clarified and she earned the right to remain in the nursing home to die. Some sort of an equally effective marker is needed for residents receiving nonhospice comfort care.

Third, at least in these two nursing homes, comfort care provided by nursing home staff was not well operationalized. "Comfort care" was documented as the care plan goal in the medical record, but indication of what was meant by comfort care, or how comfort care differed from care-as-usual, was lacking in the chart and in practice. Neither nursing home demonstrated a systematic process for anticipating, assessing, or addressing resident comfort needs. Rather than representing an overarching goal of care, attempts at comfort care were piecemeal. Staff, in particular nurses and social workers, may benefit from training to work with residents and family to fully assess and address comfort care preferences when hospice is not involved.

These findings have implications for research. Scholarship is needed to build understanding of the conditions under which people (residents, family, staff, and physicians) believe that a care plan dominated by comfort care is appropriate. Research related to developing methods for building and maintaining consensus regarding goals of care is also needed. It is important to document the extent to which resident quality of life and quality of care are related to care plan goals. Also, are certain care plan goals associated with higher family and staff satisfaction?

Research is needed to determine if the four dying trajectories by Lunney and colleagues (2002) are related to the social interaction categories presented here. For example, are social interactions associated residents with dementia more likely to be in the *dying allowed* category and social interactions related to residents with failing hearts more likely to be in the *not dying* category? If so, what are effective interventions for nursing home staff and physicians to use with families and residents to help promote better communication and deliver better care for residents in each dying trajectory?

The findings from this study underscore the difficulty that can be encountered when attempting to achieve and maintain consensus about nursing home residents' goals of care. Better methods for determining, articulating, and operationalizing goals of care for nursing home residents are needed. More attention to the comfort care needs of all nursing home residents, regardless of "dying status," is called for.

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